

The Importance of Evidence-Based Research on Self-Management for Chronic Disease

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Director, National Institute of Nursing Research*

**The 8th Annual NIH Pain Consortium Symposium on
Advances in Pain Research**

Natcher Conference Center
May 29-30, 2013

<http://painconsortium.nih.gov/index.html>



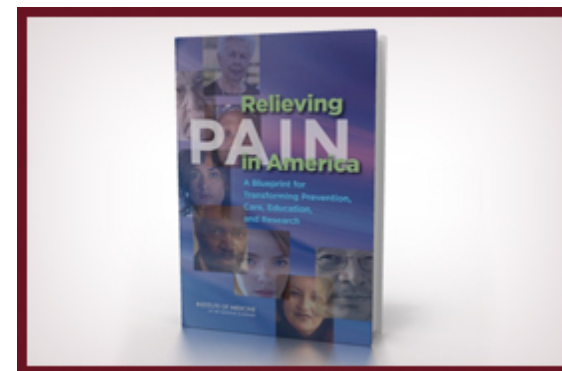
National Institutes
of Health





The NIH Pain Consortium

“Given the burden of pain in terms of human lives, dollars, and social consequences, actions to relieve pain should be undertaken as a national priority.”



“Pain is a topic of interest to virtually every NIH Institute and Center and should benefit from this type of collaboration.”

IOM: Relieving Pain in America. A Blueprint
for Transforming Prevention, Care,
Education, and Research : 2011



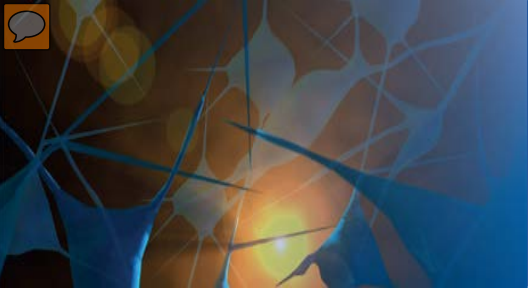
The NIH Pain Consortium

Mission

The NIH Pain Consortium was established to enhance pain research and promote collaboration among researchers across the many NIH Institutes and Centers that have programs and activities addressing pain.

Goals

- Develop a comprehensive and forward-thinking pain research agenda for the NIH, building on past efforts
- Identify key opportunities in pain research, particularly those that foster multidisciplinary and trans-NIH participation
- Increase visibility of pain research - both within the NIH intramural and extramural communities, including external pain advocacy and patient groups
- Pursue the pain research agenda through public-private partnerships



The NIH Pain Consortium



Executive Committee

- Dr. Story Landis, Director, NINDS (Chair)
- Dr. Josephine Briggs, Director, NCCAM
- Dr. Patricia A. Grady, Director, NINR
- Dr. Martha Somerman, Director, NIDCR
- Dr. Nora Volkow, Director, NIDA

Staff

- Dr. Linda Porter, Policy Advisor for Pain
- Dr. Cheryse Sankar, Policy Analyst for Pain
- Dr. Tara Schwetz, AAAS Science and Technology Policy Fellow



The NIH Pain Consortium

Current Membership

National Cancer Institute

National Eye Institute

National Institute on Aging

National Institute on Alcohol Abuse and Alcoholism

National Institute of Arthritis and Musculoskeletal and Skin Diseases

National Institute of Biomedical Imaging and Bioengineering

National Institute of Child Health and Human Development

National Institute on Deafness and Other Communication Disorders

National Institute of Dental and Craniofacial Research

National Institute of Diabetes and Digestive and Kidney Disorders

National Institute on Drug Abuse

National Institute of General Medical Sciences

National Institute of Mental Health

National Institute of Minority Health and Disparities

National Institute of Neurological Disorders and Stroke

National Institute of Nursing Research

National Heart Lung and Blood Institute

National Center for Advancing Translational Sciences

National Center for Complementary and Alternative Medicine

John E. Fogarty International Center

Warren Grant Magnuson Clinical Center

Office of Behavioral and Social Sciences Research

Office of Research on Women's Health

Office of Rare Diseases

Office of the Director

Office of Science Policy and Analysis

Office of Technology Transfer

Highlights of Pain Consortium Activities

- **Training and educational tools**
 - Centers of Excellence in Pain Education (CoEPEs)
- **Development of clinical research resources**
 - Low Back Pain Research Task Force
 - Stanford/NIH Pain Registry
- **Funding of pain research**
- **Increased visibility of pain research**
 - *Nature* Collection
 - Annual Pain Consortium Symposium



NIH Pain Consortium

Centers of Excellence in Pain Education



NIH funded Centers of Excellence in Pain Education (CoEPes) to develop, evaluate, and distribute pain management curriculum resources for medical, nursing, dental, and pharmacy schools to enhance and improve how health care professionals are taught about pain and the treatment of pain.

- Harvard School of Dental Medicine and Brigham and Women's Hospital CoEPE
- John D. Loeser CoEPE at the University of Washington
- Johns Hopkins University CoEPE
- Rochester Area Collaborative CoEPE
- Southern Illinois University Edwardsville/St. Louis University CoEPE
- Thomas Jefferson School of Medicine Headache Collaborative CoEPE
- University of Alabama at Birmingham CoEPE
- University of California, San Francisco, CoEPE
- University of Maryland Baltimore CoEPE
- University of New Mexico CoEPE
- The University of Pennsylvania CoEPE
- University of Pittsburgh CoEPE: Pain Challenges in Primary Care



The NIH Pain Consortium Chronic Low Back Research Task Force

Goals

Creation of consistent standards for terminology, classification, data collection, and outcome assessment of chronic low back pain (cLBP) to bring greater consistency to, and ultimately advance the state of clinical research on a challenging and complex problem

Outcome

An expert panel recommended development of research standards for clinical research on cLBP to include:

- Definition of cLBP
- Sub-classification scheme for cLBP by impact and prognosis
- Minimum dataset (based on NINDS Common Data Elements)



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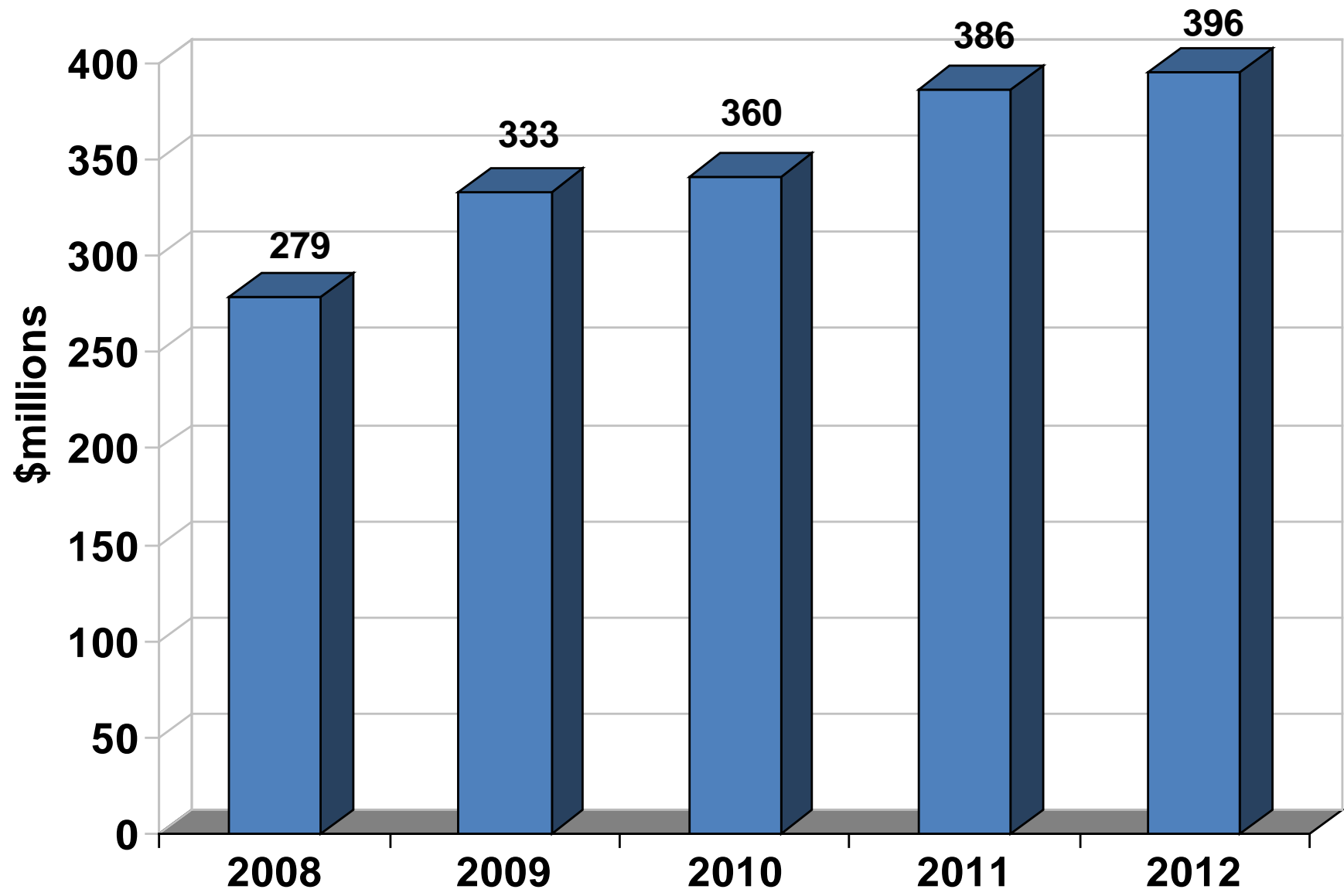


The NIH Pain Consortium & Stanford University Pain Registry

- **Partnership between NIH Pain Consortium and Stanford University.**
- **Centralized registry for tracking self-reported outcomes of chronic pain sufferers over time.**
- **Data are freely accessible to investigators for outcomes research, comparative effectiveness research, and point-of-care decision-making.**
- **Full rollout of the registry is targeted for late 2014.**



The NIH Funding Levels for Pain Research: Chronic Conditions





naturecollections

April 2013

Chronic pain





2013: Integrating Self-Management Strategies for Chronic Pain

- **Self-Management Strategies in Community Health Care Settings**
- **Tailored Self-Management Strategies for Patients and Caregivers**
- **Predictors and Indicators of Outcomes in Integrated Self-Management Strategies**
- **A Patient Perspective on Pain Self-management Strategies**



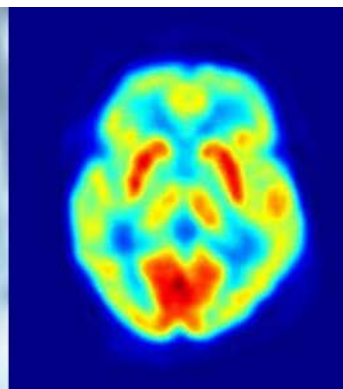
Factors in Self-management Behavior

- **Disease/condition factors**
 - Severity, regimen complexity, trajectory
- **Individual factors**
 - Age, gender, genetics
- **Psychosocial characteristics**
 - Depression, self-efficacy, integration
- **Environment**
- **Family factors**
 - Socioeconomic status, structure, function
- **Health care professionals**



Research Challenges

- **Variability and complexity in self-management approaches**
- **Dearth of randomized controlled trials**
- **Chronic pain is complex and accompanied by comorbidities**
- **Requires multiple disciplines**



Collaborative Care for Chronic Pain in Primary Care

Institution: Kaiser Foundation Hospitals

NIH Institutes Providing Oversight: NINDS & NIDA

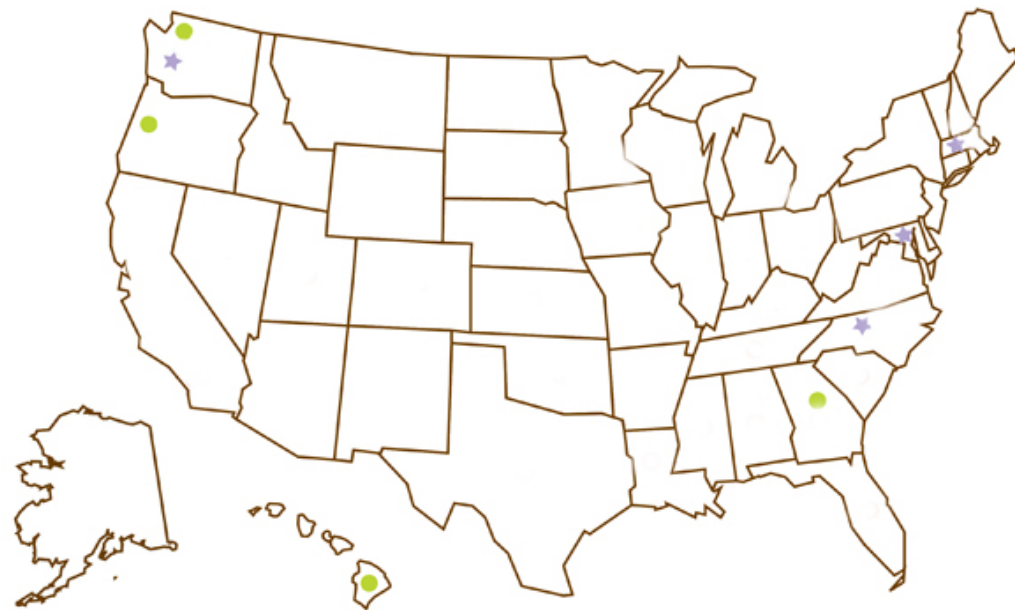
Description:

- Conducted in primary care settings
- Combine a number of treatment approaches, including physical therapy and psychological interventions
- Patients will be supported to take a more active role in managing their pain
- Primary care providers will receive additional support and guidance in treating patients with chronic pain



Lynn DeBar, PhD

NIH Health Care System Research Collaboratory



★ Collaboratory Coordinating Center

● Chronic Pain in Primary Care

Additional sites to be determined

The NIH Pain Consortium Symposium





Dynamic Tools to Measure Health Outcomes from the Patient Perspective

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Revised PROMIS Domain Frameworks

The PROMIS domain framework has been revised to group domains by Adult Self-Reported Health and Pediatric Self-/Proxy-Reported Health.

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Researchers

Provides efficient, reliable, and valid assessments of adult and child (pediatric) self-reported health

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- [PROMIS Instruments Selected References](#)
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Clinicians

Provides data about the effect of therapy that cannot be found in traditional clinical measures

- [Common Questions About PROMIS and Its Instruments](#)
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Patients

Measures what you are able to do and how you feel

- [More on PROMIS](#)
- [What Patient Reported Outcomes \(PROs\) Are](#)
- [PROMIS Measures](#)





NIH Funding Opportunities: Pain and Self-Management

Funding Opportunity	Expiration Date
Practical Interventions to Improve Medication Adherence	1/8/2014
Chronic Illness Self-Management in Children and Adolescents	1/8/2014
Pain in Aging	1/8/2016
Understanding and Promoting Health Literacy	5/8/2016
Mechanisms, Models, Measurement, & Management in Pain Research	5/8/2016

<http://grants.nih.gov/grants/guide/index.html>



The 8th Annual NIH Pain Consortium Symposium on Advances in Pain Research

Emily Dickinson on pain
"It has no future but itself"

<http://painconsortium.nih.gov/index.html>



**Pain Self-management:
Barriers and Opportunities for Improved Care**

David A. Williams, PhD
University of Michigan, Ann Arbor